

# Clark County Parent Coalition

## Message from Darla

*Summer greetings,*

*I hope this letter finds you all in good spirits and enjoying summer traditions. The boys and I have had a nice quiet summer so far, swimming in the river, visiting grandma and grandpa, and just hanging out at home. We do have a couple of small family vacations planned around this wondrous state of ours. With luck these will take place in August.*

*My summer office hours are a little more in flux than usual. I apologize ahead of time if I am hard to get hold of. Please leave a message and I will get back to you as soon as possible, or call me at home if it is more urgent. Life resumes as normal September 5, with the start of school. Be sure to check out our back to school page for resources and information to help make the transition from summer to school year easier!*



Darla Helt Coordinator,  
Clark County  
Developmental Disabilities  
Parent Coalition  
360-397-2130 ex 7862  
Darla.Helt@co.clark.wa.us

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August /September 2001

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## Legislative Update....

### Final 2001-2003 Biennium State Budget Highlights



- No cuts to adult Medicaid dental and vision
- No cuts to Adult Day Health Centers
- A \$0.50 per hour wage increase for DD service providers (respite and personal care providers)
- \$2 million for high school transition graduates' employment / day services
- No New dollars for Family Support
- No funding for low-income housing
- No funding or legislation for a Developmental Disabilities (DD) Ombudsman
- No funding for Choice (moving from institutional to community living)



# Support Groups...Conferences...Training's

## Autism Support and Training

3rd Tuesday of the month @ Arc of Clark County 7-9 p.m., contact Darla, or Monica (397-2130)

August -Behavior as Communication, Sept. Legally defensible programs for children with Autism.

## Asperger's Syndrome & High Functioning Autism Support

2nd Thursday of the month @ SWWMC 7-9 p.m., contact Andrea (694-2244)

## NW Down Syndrome Parent Support

1st Wednesday of month 6:30-8:30 p.m., contact Sunday Sheely (834-5686)

**August 19th Annual Picnic ; September 5th Dr. Prescott; Oct. 14th Annual Buddy walk**

## Parent to Parent Support

2nd Thursday of month @ Arc of Clark County 7-9 p.m., contact Kristi (254-1562)

## Parents of ADD/ADHD/ODD

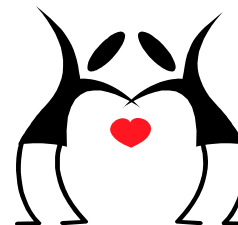
Meets 1st and 3rd Tuesday of month 6:30-8:00 p.m., contact Dixie (771-0259)

## Parent Social

1st Thursday morning of month @ Barnes & Noble Book Store (coffee shop) 9-11 p.m. , contact Kristi or Tammy @ 254-1562

## Tourette Syndrome

2nd Tuesday of each month 7-8:30 p.m., contact Danielle Martinson (571-5439)



## Special Education and The Law:

The 18 annual PNW institute on Sp. Ed. And the Law. Yakima WA. October 1-3,  
For registration information or questions call Darla @ 397-2130

## ESD 112's Autism Cadres First Conference October 12 & 13

This conference on all aspects of autism will be held in Vancouver WA. A hosted by ESD 112 and the Autism Cadre. questions call Darla (397-2130)

## "YOU ARE THE EXPERT"

Celebrating Families: The Heart of Success: 2nd Annual Parent Conference Oct. 12, 13, and 14 for information call 1-800-5-PARENT.

## 6th Annual Family Conference on Cerebral Palsy

November 2 & 3 , contact Helena Tolliver At U.C.P. of OR. & WA. For more information

## Celebrate Wellness II

A statewide conderence promoting the health and wellness of oregonians with disabilities. Hosted by Oregon Health and Science University, October 15 & 16 in Eugene Oregon.



## Information to share....

### E-mail Support Group

Our e-mail support group is growing. We now have over 30 members! This is a great way to keep in touch with other families in the area who are dealing with the same challenges and joys you are.

Please join our list by sending an e-mail to

[Parenttoparentconnectionssubscribe@yahoo.com](mailto:Parenttoparentconnectionssubscribe@yahoo.com) or contact us at [Chris-tij@areofclarkcounty.org](mailto:Chris-tij@areofclarkcounty.org) and she will subscribe you directly.

### Care Organizers Available!

The Care Organizer is an organizational tool for families in Washington State who have children with complex health care needs. Modeled after the Care note book, the Care organizer is a sturdy expanding file folder labeled with categories for important numbers /contacts, medications therapies, test results, appointments, finances and more.

♦ The Care Organizer: Helps families keep important information about their child in one central place. Facilitates communication and care planning between families and providers. Uses symbols and simple words to support use by low literacy families. Is available in English and Spanish.

♦ You may request copies from Moore North America by calling 206-622-0384 or 1-800-826-9873 and ask for the "Care Organizer" (specify Spanish or English). Organizers are mailed at no charge to you.

## Leadership Development Institute

We are in the process of recruiting for participants in our Leadership Development Program. If you or someone you know might be interested in a program that will develop leadership skills and knowledge in the disabilities field, we hope to hear from you. It is a one year program that includes six workshop weekends, followed by a six month mentorship.

The goal of the Clark County Leadership Development Program is to provide information, training, and skill-building experiences to program participants on disability issues locally, state-wide, and nationally. We have chosen six workshop sessions with homework assignments between workshops and a mentorship/internship as our training format. Participants will serve as future leaders in the disability's movement.

If you are interested in receiving an application packet, and an overview of the program please call me at 397-2130. I will be more than happy to answer any questions you might have about the program, and/or the application process.

## Attention – Invacare Power Chair Recall

Invacare has recently discovered that on rare occasion, an electrical short may occur that is not protected by its existing 60 amp fuse. In order to insure the safety of our products, additional 15 amp fuses have been designed into the system. If you have an Invacare power wheelchair purchased between 1988 and June of 2000 please contact the dealer from which you purchased your chair to have the replacement kit installed on your wheelchair.



If you cannot locate your original dealer, contact Invacare Corporation at 1-800-333-6900 and select Option 8 and they will direct you to an Invacare Service Center.



## Decision Making that Respects Personal Rights & Choice

"In their eyes, I was mentally retarded. Nothing I wanted to say was worth listening to." The words of Ray Gagne in *A Self Made Man*, the story of his life is a too-common experience of many individuals with developmental disabilities. If no one's listening, you do not have an effective voice.

Washington state law provides a variety of methods for a court to authorize surrogate decision makers who can assist a legally "incapacitated" person to make decisions important to his or her well-being.

But every individual with a legally authorized surrogate decision maker retains significant civil and personal rights. Legislative intent is that a guardian's judgment will be called upon to assure that a person's health, safety and finances are protected (RCW 11.88.005), and that his or her "best interests" are met — not to make all decisions for a person.

*The following are excerpts from a recent workshop in Bellingham by David Lord, an attorney with Washington and Advocacy System (WPAS). For more information, see [www.wpasrights.org](http://www.wpasrights.org).*

### **Important qualities of a surrogate decision maker:**

- ⇒ Able to communicate with the person. Patient. Persistent. Encouraging of communication. Supportive.
- ⇒ Respects the rights of the person and his or her expressed interest. Defends the right to least restrictive actions.
- ⇒ Knowledgeable about the person's life, preferences, goals, strengths and abilities, family, friends, dreams.
- ⇒ Able and willing to advocate on behalf of the person. Knows or finds out what options are available. Has a consistent attitude of "How can I make this happen?"

### **Steps in surrogate decision making:**

1. Starts with what the person wants. Maximize the person's participation. Be creative and determined in your communication.
2. Understand the person's rights and your role in protecting those rights.
3. Identify the person's underlying interests and preferences, expressed over time. Consult others too.
4. Assist the person in carrying out his or her own choices.
5. If you anticipate likely harm from those choices, consider what benefits and harm may result from overriding that expressed choice, as well as from honoring it.
6. Is it actually necessary to override the person's expressed choice in order to protect his or her rights?
7. Identify the least restrictive options consistent with the person's choice and interests.
8. Make a decision. Explain it to the person.



## Questions & Answers on Guardianship

**What is a guardian?** A guardian is a person appointed by a court to manage the affairs of a person who is “incapacitated,” with a “demonstrated inability” to adequately manage property or financial affairs, or to adequately provide for his or her own nutrition, health, housing or physical safety.

**How is a guardian appointed?** Guardians are appointed in response to a petition asking the court (1) to determine that the person identified is incapacitated, and (2) to appoint a guardian. The person identified in the petition must be notified. The court appoints a guardian ad litem to investigate and report to the court. A hearing must be held.

**What if the person doesn’t want a guardian?** A person may state his or her objections at the hearing, and has the right to be represented by a lawyer. A guardian may only be appointed if, after the hearing, the court is convinced that a guardian is needed.

**What if someone can still do some things for themselves?** Limited guardianships can specify what types of assistance are needed from the guardian. Guardianships are intended to meet a person’s specific needs.

**What are a guardian’s responsibilities?** A guardian of the estate is responsible for managing a person’s property and finances. A guardian of the person is responsible for assessing a person’s physical, mental and emotional needs, implementing a care plan to meet those needs, and may also be responsible for giving or withholding consent to medical treatment. Annual reports to the court are required of all guardians.

**Are there decisions a guardian may not make for a person?** Yes. A guardian may not place a person in a residence against his or her will. A court order is required for commitment for mental health treatment, for some types of therapy and for use of physical restraints or restricting freedom of movement.

**What happens to someone’s legal rights when a guardian is appointed?** In a full guardianship, the person loses the right to make most decisions. In a limited guardianship, the guardian’s area of decision-making is defined. In either case, the guardian’s responsibility is to make decisions that are consistent with and respectful to the person’s expressed preferences and values.

**Can a guardianship be modified or terminated?** Yes. A person can discuss his or her concerns with the guardian, if that makes sense, or write directly to the court to request a change or termination of the guardianship.

**Isn’t a power of attorney an easier alternative?**

Yes and no. A power of attorney appoints an agent to act on someone’s behalf. This power can only be given by a person who is not incapacitated.



# 2001 Self-Directed Services Update



## 1. Information/Education Initiative

A. Region/county/parent/self-advocate partnerships have begun. Regions are having meetings with their counties and constituents and putting out RFPs for various projects, including information/education and funding for parent-to-parent, parent coalitions and self-advocate groups.

B. A policy is being worked on that will require core information to be delivered at intake, eligibility, planning times, and other strategic periods for people who use DDD services. Information has been gathered from families and self-advocates. A meeting was held with regional information and eligibility coordinators and they are going to draft a policy that can be distributed for input and consideration/revision by community advocates and the DDD Stakeholder Workgroup.

C. Information for self-advocates, family groups, DDD staff, providers, etc. has been developed and is being disseminated upon request. If you need any particular information, please let me know. We are ready to help out in anyway we can.

## 2. Personal Agents

A final recommendation on this function, using the draft document that is in the Stakeholders' plan needs to be finalized. This is part of the "Role of Government" discussions that are currently underway and a resolution will hopefully occur soon. The role of the personal agent, as well as needed training, how the services are paid for, and other issues need to be finalized. It is important to get this worked out, so it can be available for those needing or desiring additional help.

## 3. Olmstead Activities

Work has begun on putting together a plan to offer people who have the opportunity to use Olmstead funding, used in a self-directed way, if they desire to do so. For those people who choose to move from the RHCs or are ready to leave Eastern or Western State Hospitals, we are working on ways to offer them individual budgets; the opportunity to manage those budget to the degree they feel comfortable; personal agent services, if desired; the opportunity to look at a wide array of possibilities; and quality assurances.

## 4. Birth-to-Three Policy

A task force of interested parties (parents, providers, ITIEP personnel, etc.) around the issues of how to include families with children birth-to-three in self-directed services is going to begin in July. The group anticipates meeting four times to address the issues involved and to make a recommendation to the Stakeholders at the end of that time. Sandy Loerch, director of the ITEIP program will co-sponsor the meetings.

## 5. Residential Unbundling Policy

A workgroup of providers met, under the direction of Colleen Erskine (DDD) and Joan Wright, residential provider, to consider the issue of people who choose to leave a residence, but the funding is co-mingled with people who do not choose to leave. Their proposed draft policy will soon be available for review and comment.

## 6. Assessment Tool

As we work on deciding on an assessment tool that will meet the needs of our state, the NCSNAP rater-reliability study will be continued through August. One more round of assessments has been added and then the results will be shared with stakeholders after that date. Case managers have been trained and have done the two sets of assessments. They are now ready to do the third round and then the results will be in the hands of the Office of Research and Data Analysis (ORDA) for analysis and review.

## 7. HCFA Grants

A.. Each state is allowed to submit one grant proposal for the "Real Choice Systems Change Grant," and DSHS has not yet made a decision on what that proposal will include. They have held two meetings to solicit input from participants in DSHS services, and have asked for applications from interested people to be on a Consumer Task Force. After all input is collected, they, along with the Consumer Task Force, will make a final decision on what to submit. Kathy Wiggins, who was formerly with the Governor's Office has been hired to coordinate the process.





(2001 Self-Directed Services Update – cont. from page 2)

7. B. DDD is working with Aging and Adult Services (A&ASA) on a proposal for the grant that addresses “Community-Based Attendant Services with Individual Control.” It will focus on recruitment, retention, teaching employer skills to those who use the services of individual providers and quality assurance.

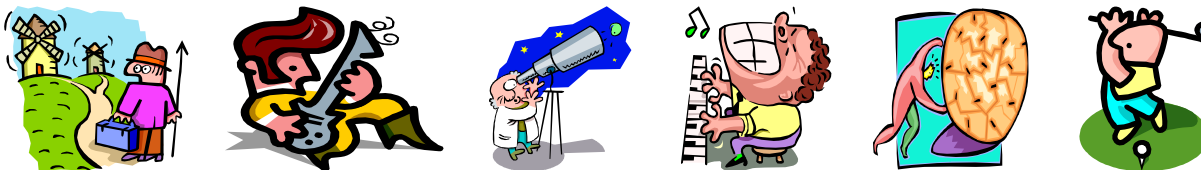
C. “The Nursing Facility Transitions” grant will be applied for by A&ASA, to work on removing obstacles to moving younger people with physical disabilities and people with developmental disabilities out of nursing homes and into community settings if that is their desire <<http://www.IEfunding.doc>>.

#### **8. E-mail Updates on Self-Directed Services**

In April an e-mail list serve was started to keep people who are interested informed on what is happening with self-directed services in the state. Items will be sent out routinely as new information is available.

#### **9. Regional 5 Quality Assurance Pilot**

The draft final report of the pilot activities and their findings and recommendations will be available by July 1. This information will be presented to the Stakeholders for their recommendations on future use of the model. This pilot was focused on people who use the services of individual providers and asking through questionnaires, telephone surveys and face-to-face visits about how their needs are being met.



Let's help them to build a life to look forward too! What is in your dreams????

## **PEOPLE FIRST of Clark County**

We are people first...our disabilities are secondary!!



August Picnic!!!  
Tuesday, August 21, 2001 5:00 –7:30 p.m.  
Orchards Park



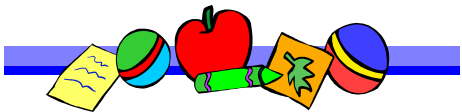
If you have any questions, or would like to join – please call Kris at The Arc 254-1562, ext.18

## **New Toll-free Number for Reporting Abuse**

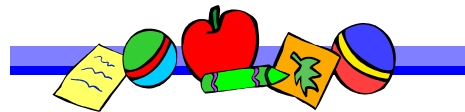
A new toll-free number for reporting abuse or neglect of a child or vulnerable adult in Washington was unveiled April 6, 2001, by the state Department of Social and Health Services. The number **1-866-ENDHARM** or **(1-866-363-4276)**, directs callers to the appropriate DSHS office to handle the complaint. For more information about reporting abuse or help with other questions, visit the DSHS web site at [www.wa.gov/DSHS](http://www.wa.gov/DSHS).

**Please Remember:** If you are calling about an immediate life-threatening emergency always — Dial 911.





## Back to



### **IEP Mentors..**

Remember we have a team of volunteers who are trained parents of children with special needs that are available to attend IEP meetings with you. They have lots of good experience, and training around SP Ed issues, but can also just come and take notes if needed. It is helpful to have a pair of non biased ears to listen, and an extra person to help ask questions. If you are interested in accessing a IEP mentor, or interested in becoming one, please call Darla at 397-2130, and I will connect you.

### **Home Schooling**

A local mom who home schools her special needs daughter has just started "Home schooling Special Needs Kids in Washington State" If anyone is interested you may sign up at <http://groups.yahoo.com/group/SpecialHSofWA>

### **Home and School Connections**

When home and school work together, students learn more. Here are some ways even busy parents can work more closely with their children's schools:

- ◆ Get to know your child's teacher, no matter what age your child is.
- ◆ Attend parent – teacher conferences., and keep in touch between meetings.
- ◆ Join your school's Parent Teacher organization or shared leadership team.
- ◆ Stay informed, and help the staff stay informed of changes with your child.
- ◆ Consider spending a day at school. If you can't manage a whole day, try one hour , or go have lunch with your child.
- ◆ Serve on school or district advisory group.
- ◆ Remember you are your child's best advocate!
- ◆ Part of our job as parents is to educate others on our children's specific needs.
- ◆ **Build relationships with your child's team**
- ◆ **Remember to choose your battles. "Some time's it is worth losing a battle to win a war!"**



### **Congratulations Clark County School districts!!!**

Special Education Safety Net funding awards received!

The Office of Superintendence of Public Instruction ( OSPI ) has announced the special education safety net funding for the 00-01 school year, and Clark County Schools come out on top! These are funds awarded to school districts in addition to the state and federal special education funds that all Sch. Dist. receive. The special education funds are provided as an enhancement to the general education dollars that every student receives.

Vancouver Sch. Dist. Awarded -\$698,865.00

Camas Sch. Dist. Awarded - \$209,937.00

Evergreen Sch. Dist. Awarded - \$262,813.00

Washougal Sch. Dist. Awarded -\$165,599.00

Battle Ground Sch. Dist. Awarded -\$273,333.00

ESD 112 Co-op Awarded - \$153,103.00

Stevenson/Carson Sch. Dist. -\$99,380.00







**A Hundred Years From Now**  
...it will not matter what my bank  
account was, the sort of house I lived in,  
or the kind of car I drove.... But the  
world may be a better place because I  
was important in the life of a child.

## **20 Steps to Getting A Good IEP**

**By**  
**Reed Martin**

### BEFORE THE MEETING:

1. Chart needs of your child that affect the child's ability to meet all of the school's expectations for a typical student, including transition successfully after public education.
2. Examine all records relating to your child.
3. Review last year's performance.
4. Determine if additional evaluation is needed.
5. Let the school know in writing before the IEP meeting what you want that will be different, and remind the school of their duty to reply in writing whether they will accept or refuse your proposal.
6. Make sure the proper people will be at the IEP meeting.

### AT THE MEETING:

7. Object, on the record, to procedures that discourage parental participation, and consider re-scheduling the IEP.
8. Describe problems your child has that affect "educational" benefit.
9. Set goals in each problem area, with appropriate consideration of transition.
10. Select interim objective.
11. Set evaluation schedules and criteria for each objective and goal, including the parent's role in assessment effectiveness.
12. Develop the plan.
13. Determine needed related services.
14. List resources to be allocated.
15. Examine contingencies, such as absence of key personnel or disciplinary infractions.
16. Determine where the program will be carried out.
17. Remove any unnecessary restriction.
18. Plan the transition component.
19. Monitor progress.
20. Prepare for the next IEP or call for the revision of the current one if there is a lack of expected progress toward the annual goals.



DARLA HELT COORDINATOR,

## SOCIALS AND GATHERINGS

Clark Newsletter Date



**Play date in the Park!** August 7, 14, and 21 from 11 am to 1 p.m. @ Orchards Park. Everyone welcome, bring your lunch and join us!



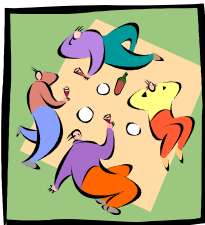
**Parent to Parent pizza social** – August 16, from 6-8 p.m. at Round Table Pizza by the mall. For more information call Christi, or Tammy at 254-1562.



**Free Time** - August 16, and Sept. 6, 13, and 20, from 6:30 – 9:00. For children with developmental disabilities and their siblings ages 2 to 10. Pre-registration is required to register or for more information call Christi or Tammy 2 254-1562.



**Sib Shop** – For siblings of children with developmental disabilities ages 5-13 yr. The last Saturday of the month. Call Janet or Kris 2 254-1562 to register or for more information.



**2nd Annual Back to School Luncheon** – Calling all parents it is almost time for our annual celebration of the start of school! We will be having a salad potluck at Darla's house on September 19, from 11:30 – 1:30. Everyone is welcome, for more information and/or directions call Darla @ 397-2130!



**Coffee Social @ Barns and Noble** – The first Thursday of the month from 9 am – 11 am in the coffee shop. Call Christi or Darla for

